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ABSTRACT

Case studies of two students with pervasive developmental delays illustrate the conflict between belief-based versus measurement-based approaches to planning educational services for students with diverse abilities. The doctrinaire view embraces inclusion as an end in itself. Placing students with diverse abilities, even severely handicapping conditions, in regular classrooms is itself the goal. Teacher preparation, social acceptance by peers, and classroom modifications are details to be worked out later. The rational inclusion view sees inclusion as an ongoing process. The preparation of the teacher, classmates, and other classroom variables are seen as necessary prerequisites to the eventual placement of the student in the regular classroom. Individual students with similar diagnoses may require different educational services, each of which may be consistent with inclusion for that student. These options should be evaluated on their merits. Team members preparing IEPs often choose a path on the basis of personal preference as if it were an immutable decision. When the discussion is couched in terms of "right or wrong" rather than in a problem-solving mode, it is difficult to formulate compromise options such as trial periods and measured progress. Teachers who are problem-solving oriented; team leaders who are independent and skilled; parents with access to training and information; and the use of more rational, versus doctrinaire, approaches will result in more successful school inclusion. (TD)

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Educating Students with PDD/Autism: The Case for Rational Inclusion

Introduction

Three issues have been identified by Simpson (1995) as having "a significant effect on the education of children with autism: (a) a willingness to accept and rely upon unproven and controversial interventions, (b) the advisability of full-time placement of students in general education settings, and (c) the preparation of adequately trained personnel to educate students with autism." This list can be expanded to contain "doctrinaire views of school inclusion". Planning and implementing services for students diagnosed with PDD/Autism (Pervasive Developmental Delay /Autism) often results in friction among team members. Splits between parents and school staff or between differing camps of school staff members are common. These splits commonly occur along predictable fault lines related to themes such as "use of structure/medications", "assessing progress", "curriculum elements", and "school inclusion". These splits have significant impacts on the development of IEP related services, evaluating student progress, and the erosion of trust among team members. Since these factors in turn affect resource allocation (i.e. budget), they have grave implications for rural school districts struggling to serve a most difficult population of students. The cases of two students from different school districts will be examined to illustrate these splits, their origins, and suggestions for amelioration

Case Studies

Student Profile - JP

JP is a 6 year old boy variously diagnosed with Severe Developmental Delays, PDD, or mental retardation who lives with his single mother. He exhibits no expressive language other than saying "mama". He shows scant evidence of receptive language beyond responding to his name and a few one word instructions(e.g. "sit", "stop", "eat") which are often repeated 3-4 times before he initiates the task. He is a visually oriented child who can often imitate one to two step activities which are either modeled or demonstrated for him with hand-over-hand techniques. His social repertoire is grossly immature, limited to gazing and smiling at a 1:1 teacher or parent, listening to oral reading or stories, being tickled, or allowing someone to squeeze his head. He is dependent on mother or teachers for hygiene and activities of daily living. His physical development and strength are increasingly an obstacle for all his service providers, two of whom are often needed to manage him.

Service Profile

After conducting a thorough evaluation, his pediatric neurologist recommended that JP be placed in a highly structured residential school. This recommendation was based on the doctor's recognition of JP's severe delays in development and subsequent service needs which he felt

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would be difficult for JP's mother to provide. While admitting that caring for JP and his younger sister was difficult, JP's mother found this alternative unacceptable. She cried whenever the topic was mentioned. JP's tantrums and uncooperative behaviors at home were so disruptive that she requested and received psychotropic medications from the doctor to render JP more manageable.

The urban school district, having recently set up a day program for students diagnosed with PDD/Autism, was eager to accept JP. The school program provides a range of classroom activities, speech, OT, and physical therapies and home-based family support components geared to students diagnosed with PDD/Autism and their families. The classroom teacher is well trained and experienced in teaching these students. She makes every effort to use a "data based" approach to making classroom decisions. The classroom teaching assistants have little education beyond the high school level and no prior experience of a technical nature regarding education generally, let alone the complexities of teaching students with complex learning or behavioral needs. Their classroom teaching approaches reflect their personal view of parenting. Some approach each teaching situation as an opportunity to hug the student or fulfill a perceived emotional need. Others react to each situation as an opportunity to demonstrate that they will not "give in" to a student's misbehavior. The classroom teacher provides ongoing training and supervision as time permits.

Congruence and Conflicts

1. Structure/Medications. The physician continues to prescribe a range of medications as behavior management agents based on the mother's description of JP's unruly behavior. This coincides with her need to alleviate the pressures on the household. The teacher struggles with the behavioral side effects of each new medication regimen (e.g. hyperactivity, drowsiness) and the problems they pose to JP's attention, learning, and cooperation skills. The teacher's attempts to send classroom behavioral data to the doctor, as feedback on the side effects of each medication emerge, have been rejected.

2. Assessing Progress. The teacher instructs her assistants to observe and collect classroom data relevant to JP's learning progress and disruptive behaviors (e.g. tantrums, naps). The mother is unable to collect data and is mistrustful of how it will be used. Each of the classroom assistants vary in their application of teaching techniques, use of reinforcement and punishment, and data recording. Data assessment does not permit distinctions between changes in JP's behavior which may be due to changes in techniques, staff persons, medications, or other factors. The doctor continues to make treatment decisions without consulting with school personnel.

3. Curriculum. JP's teachers and mother design an IEP that emphasizes the development of communication, self help, and behavior management skills. The mother cannot attend training sessions and is reluctant to have home visitors. Each time JP's behavior becomes problematic, his mother approaches the doctor for increases or changes in his medications. As the new medications take effect, JP shifts from drowsy to hyperactive or vice versa. As his behavior patterns shift, the classroom teacher abandons old strategies for new ones. Sometimes the medications cause JP to show different patterns of behavior in the home and school settings. It

may take two months or more before the teacher and the mother can reach agreement to approach the doctor again. In the meanwhile, assessing JP's progress in any particular skill area has become even more difficult.

Conflicts

The predisposition of JP's doctor towards residential school placement created an emotional rift with JP's mother and a treatment rift with the school staff. JP's mother is concerned about how sending her young son to a residential school might affect him or her relationship with him. She is also concerned about what others will think about her if she sends her son away. So JP remains close to his mother and sister in a very unstructured home where he receives psychotropic medications which interfere with his attending, learning, communication, and memory skills.

Assessing JP's progress is made difficult by the various teaching styles, medications, and communication gaps among his providers. His mother is afraid that if she collects behavioral data, it will reflect on her as a mother or worse, be used as a basis for sending her son away.

The classroom staff work together at a general level on JP's communication, self help, and behavior management skills. On a more careful examination differences in each person's understanding of PDD/Autism, the importance of measurement, or their individual notions of school inclusion seems to affect the efficacy of teaching approaches. The school district adhering to its own version of "school inclusion" has created a program for **all** PDD/Autistic students. This program is in a public school building but is largely isolated from other students. The program relies on 1:1 teaching assistants but does not adequately train them. Sending a student to an (expensive) out of district placement is not easily done within current district inclusion guidelines. At team meetings each participant has trouble weighing suggestions on their merit rather than on the predisposition of the person making the suggestion.

Student Profile - BW

BW is an alert, verbal 5 year old boy diagnosed with PDD. He lives in a suburban rural community with his parents and an older brother. He is highly verbal, social, and attentive. There are elements of stereotypy, ritual, and decalage in all his repertoires but he does not present significant behavior problems or seizures. He was diagnosed at three years of age and has received educationally related services since then. For the past two years BW has been a day student at a highly structured behaviorally oriented facility specializing in teaching students with autism and severe behavior management problems. Parents and teachers agree that BW made tremendous progress his first 11/2 years at the special school. The family has become increasingly concerned about BW's social skill development.

Service Profile

For 11/2 years BW made progress in a highly structured behaviorally oriented facility. The school district has strong commitment to school inclusion for most students but seems relieved to have a specialized program near by to serve students with complex needs. As long as the parents are satisfied, the school district would rather send these students out than retrain teachers or make other modifications that they feel might be necessary to mainstream these students. School district personnel in this quiet, rural, well ordered town are very concerned about the possibility of reactions from parents of other students to any odd or disruptive behaviors BW might exhibit. They ask," Don't all students have the right to feel safe in the classroom?". The parents feel that the private facility is an isolated setting which does not provide age appropriate roll models or a chance for real peer acceptance for BW. Ironically, the staff at the behaviorally oriented facility feel that BW should stay with them a bit longer, but do not offer any measurable criteria for assessing the change in placement.

Congruence and Conflicts

1. Structure/Medications. BW has enjoyed the benefits of a highly structured data driven program for almost two years. The family wishes to begin fading BW into a typical classroom, but the school district is not anxious to make the necessary accommodations just as the private facility is not anxious to let go.

2. Assessing Progress. There is no disagreement on the progress BW has made towards his learning objectives at the private facility. There is also no disagreement among those concerned that much of the progress is due to the highly structured data driven procedures used at the facility. It is difficult, however to independently assess BW's "meaningful" progress because the staff at the facility determine which data will be shared. Generalization data about BW's performances in other settings or with variants of the target behaviors is not presented to the team. The situation is made more complex by the cult-like closed atmosphere in which the private facility operates. Parents must make appointments well in advance to visit or observe their child. Other family or school hired advocates or consultants are often forbidden to visit except under the most controlled circumstances. The argument of the private facility is that these safeguards are an attempt (in the children's best interest) to protect students from outside disruptions. BW is making progress but who decides the areas of his progress?

3. Curriculum. There are some questions about the appropriateness of BW's learning objectives and about the direction they are leading. If time is critical, is it more important to teach a student to count to a hundred or a thousand, or to teach the student to relate to peers? Obviously both these kinds of objectives are important. But in such a labor intensive teaching situation, where learning relies so much on structured classroom teaching, how are the learning resources to be organized? Each interpretation of "school inclusion" tilts the path in its own direction. How shall numerical data be collected? How will data be used to assess the fading of highly structured techniques?

Conflicts

There are rifts among BW's team members about the appropriateness of BW's learning objectives and the general direction of his IEP goals. There is also a rift over when and how to mainstream BW into the public school community. Each team member offers solutions consistent with their parochial view of educational doctrines. Disparate interpretations of school inclusion are offered as justification for keeping him in a specialized facility and for relocating him to a public school classroom. The parents find themselves disagreeing with both the school district's and the private facility's versions of school inclusion. They are trying to negotiate a gradual approach of introducing BW to a typical classroom which is assessed according to the principles of Applied Behavior Analysis. It is an uphill climb.

School Inclusion and Students Diagnosed with PDD/Autism

Discussion

Until recently, students diagnosed with PDD/Autism were categorically excluded from public schools. According to prevailing educational doctrines, these children were thought to be psychotic. Only since the 1960s have they been viewed as teachable. Lovaas' demonstration (1963) that severely autistic children could learn through highly structured versions of the same methods used with typical children extended not only our view of the abilities of autistic students but of which students could be taught in the public schools. The work of Kozoloff (1971) pushed the boundaries even more by demonstrating that autistic students could succeed in typical classrooms if teachers, curricula, and other components of the learning environment were prepared in precise ways.

The school diversity movement has traversed a parallel course. As our definition of the student population has broadened, students differing in gender, ethnicity, and learning ability have been admitted to the classroom. The success of these students also required modifications in the preparation of teachers, curricula, and components of the learning environment. Relying on placement in the classroom has never been adequate to ensure success of students who differ significantly from their peers. Teaching and assessment approaches which do not make accommodations to fit the receptive and expressive needs of an individual student, become obstacles to that student's educational success. When education professionals are guided by their feelings rather than measurement conflicts arise as in the case of facilitated communication (Bilken,1990; Calculator,1992).

This preeminence of decisions to include diverse students in the classroom, over determinations of how to best teach them, continues to have critical implications for educators, parents, and the students themselves. This dichotomy manifests itself at every level of discussion and planning. Perhaps it is illustrative that justifications to include diverse students seem to originate in ideas about what is morally, legally, or even democratically correct. This could be seen as a doctrinaire approach to school inclusion. Later there is a shift towards the **presumed** benefits for classmates, the community, and the diverse student. Subsequent discussions about

how to effectively teach these students address measurement related concepts such as grading, assessing progress, and student productivity almost as an afterthought.

This rift between **belief based** and **measurement based** approaches to planning services for students with diverse abilities now separates groups of former allies in the special education community. One group embraces "inclusion" as a doctrine or an end in itself. This is a doctrinaire view (Stainback,W., and Stainback, S., 1984). In this view, placing students with diverse abilities, even severely handicapping conditions, in the regular classroom is itself the goal. Teacher preparation, social acceptance by peers, classroom modifications are details which can be worked out later. Placing the student in the regular classroom is the measure of success. School districts can be heard claiming that they are successfully fully included on the basis that they have placed a large number of diverse students in regular classrooms.

The other group sees "inclusion" as an ongoing process. In "rational inclusion" the preparation of the teacher, classmates, and other classroom variables are seen as necessary prerequisites to the eventual placement of the student in the regular classroom. While teachers and parents often blur the distinction between these two positions, the differences are significant and are illustrated by the case studies. Individual students with similar diagnoses may require a different array of educational services, each of which may be consistent with "inclusion" for that student. One student may need the high degree of structure specialized facilities offer, another student may not. Both these options should be evaluated on their merits. Too often teams choose one path or the other on the basis of personal preference as if it were an immutable decision. Sometimes team members out of a deep sense of personal conviction, refuse to sign or support the IEP. When the discussion is couched in moral terms of "right or wrong" rather than in a problem solving mode, these outcomes are inevitable. Where there is honest disagreement about IEP decisions team members have difficulty accessing options which resemble compromise. Trial periods and measured progress are two such options.

Conclusion

Too often students with diverse needs (and their classmates), especially those in the first included wave, serve as guinea pigs as we learn how to provide educationally related services to them in the public school. In the best instances, the learning curve of the teachers is steeper than that of the students. In the worst of cases, decisions about placement, service provision, and classroom modifications are driven by factors unrelated to teaching efficacy. Calling this a reactive approach rather than an "On the Job Training (OJT)" approach misses the irony that in these cases the rolls of teacher and student are reversed. While several factors (e.g. teacher preparation, school budgets) likely contribute to this OJT approach, we can do better.

Teacher preparation, often heavily imbued with faculty members theories or doctrines, often sets the stage for the quality of discussions in IEP team meetings. Teachers who are problem solving oriented, are less likely to view issues as "black or white". Team leaders are rarely given the preparation necessary to manage team meetings or to keep the discussion on an even keel. Frequently, the close connection between the team leader and the school administration plants a seed of mistrust before the proceedings begin. More skilled team leaders, more

independent team leaders are more likely perceived as trusted team leaders. Active parent advisory groups with access to training and information, are more likely to make informed decisions. they are also more likely to recognize and appreciate the genuine efforts of school staff without suspicion.

Finally, less doctrinaire and more "rational" approaches to defining and implementing school inclusion must be used. Successful school inclusion must stop being measured as a body count of how many students with diversity are in the regular classrooms. Successful school inclusion needs to be measured as a function of each student's academic and social success.

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